Michigan Department of Community Health
MDCH
Jennifer M. Granholm, Governor
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What is Beckwith-Wiedemann Syndrome?

Beckwith-Wiedemann syndrome (BWS) is a genetic condition that affects growth. It occurs in males and females of all ethnic and racial backgrounds. It causes rapid or uneven growth, low blood sugar and other physical features. BWS occurs in about 1 in 13,000 people.

Michigan Resources & Support

Children's Special Health Care Services
Family Phone Line
Toll-free: 1-800-359-3722
E-mail: ppp@michigan.gov
www.michigan.gov/cshcs

***Early On*® Michigan**
Toll-free: 1-800-EARLY ON
www.1800earlyon.org

Michigan Birth Defects Program
Nurse Follow-up Coordinator
Toll-free: 1-866-852-1247
E-mail: BDRfollowup@michigan.gov

Michigan Genetics Connection
www.migeneticsconnection.org

National Resources & Support

Beckwith-Wiedemann Support Network
www.beckwith-wiedemann.org/

Beckwith-Wiedemann Syndrome Children's Foundation
Phone: 425-338-4610
www.beckwith-wiedemannsyndrome.org

Beckwith-Wiedemann Syndrome Family Forum
www.geocities.com/beckwith_wiedemann

BWS Registry
E-mail: bwsregistry@kids.wustl.edu

Family Village
www.familyvillage.wisc.edu

GeneReviews
www.geneclinics.org/profiles/bws

Genetic and Rare Diseases Information Center
Toll-free: 1-888-205-2311
E-mail GARDinfo@nih.gov

How may BWS affect my child?

Learning: Most children with BWS have normal learning unless medical complications result in delayed development.

Physical: An opening in the abdomen is common. This may consist of a bulging near the belly button (hernia) or a large protrusion that contains some of the intestines (omphalocele). Kidney abnormalities, cleft palate and creases or pits in the earlobe are also common. Large body size (macrosomia) and enlarged tongue (macroglossia) are usually present at birth or develop in early childhood. Children with BWS tend to grow rapidly and are big for their age. Uneven (asymmetric) overgrowth of parts of the body may also occur.

Medical: There is an increased risk (~7.5%) for certain types of tumors. The risk appears to be the greatest during the first eight years of life. The tumors can be benign or cancerous. Low blood sugar (hypoglycemia) is common in newborns. If untreated, the child's development may be affected. Thyroid levels may be low, while cholesterol is often high.

How does BWS occur?

There are different ways BWS can occur. Most often, it is caused by changes in genes located on the #11 chromosome. The child with BWS is usually the first and only family member affected, but sometimes the condition is passed down from a parent. Genetic counseling is recommended for parents to learn about the genetic cause of BWS in their family, and possible health risks for other children.

How is BWS treated?

BWS cannot be cured, but many symptoms can be treated. The effects of BWS are seen mainly in childhood. Complications occur less often in adults. Soon after birth, low blood sugar must be treated. Surgery may be needed to repair an abdominal wall or other birth defect. Frequent screening (about every 3 months) using blood tests and ultrasound is needed to check for tumors during the first 8 years. When a large tongue is present, evaluation by a craniofacial team helps to ensure proper management. Other treatments may be needed for health problems as they arise. Infants and toddlers (birth to 3 years) should be connected with *Early On*® Michigan if there are concerns about learning, speech, or behavior; while children over 3 years of age should be referred for special education services if concerns arise. Children with BWS and their families benefit from having a primary care physician who helps to coordinate their care with medical specialists and other community-based services.

For more information, call Michigan's Genetics & Birth Defects Program toll-free at 1-866-852-1247 or e-mail Genetics@michigan.gov

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